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From ‘doctor knows best’ to dignity: placing adults who lack capacity at the centre of decisions about their medical treatment

Emily Jackson*

1. Introduction

My purpose in this article is to look backwards, over nearly 30 years of case law and legislative reform since the judiciary first derived a ‘best interests’ test for the medical treatment of adults who lack capacity from the doctrine of necessity, and forwards, in order to advocate an even more patient-centred approach. I will acknowledge that there has been a sea-change in the way in which decisions are taken for people who lack capacity, from the ‘doctor knows best’ paternalism of *Re F (Mental Patient: Sterilisation)*,¹ to the recent humane and empathetic judgments in the Court of Protection. The Mental Capacity Act 2005 was a staging post on this drive towards respect for the patient’s point of view, but the judiciary, to its credit, has taken this further still. It could be argued that the Court of Protection is now working with a presumption that the patient’s wishes should be accorded some level of primacy which goes beyond the wording on the face of the statute, and which is, importantly, out of step with how the best interests test is interpreted ‘on the ground’. In the light of this, and the UN Convention on the Rights of Persons with Disabilities,² I will advocate a slightly more structured working model, which places the adult who lacks capacity unequivocally at the heart of decisions about her medical treatment.

2. Softening the capacity ‘cliff-edge’

The central problem is that the law inevitably draws a bright line between those who do, and those who not have the mental capacity to make decisions.³ If there is to be legislation (or a common law regime) to protect the interests of those who cannot take decisions for themselves, there has to be a test for incapacity, and it is in the nature of such a test that some patients will pass it, while others will fail. The

* Law Department, London School of Economics. I am very grateful to Jonathan Herring, Carolyn Hilder, David Lock and Genevra Richardson for reading and commenting on earlier drafts of this paper, and to the MLR’s anonymous referees for their helpful criticisms and suggestions for improvement.

¹ [1990] 2 AC 1.

² The UK ratified the Convention in 2009. The UK is also a signatory to an Optional Protocol, which means that individuals are able to make complaints directly to the UN Committee on the Rights of Persons with Disabilities.

³ G. Richardson, ‘Mental capacity in the shadow of suicide: What can the law do?’ (2013) 9 *International Journal of Law in Context* 87-105.

reality of the psychological ability to exercise choice is not binary, however.⁴ In addition to the rather obvious fact that a person's capacity will fluctuate over the course of her lifetime, the ability to make decisions, with or without others' help, exists on a spectrum.⁵ At one end, there might be someone in a permanent vegetative state, who cannot express a view, while at the other end, someone may appear to be able to take decisions without others' support. Even this is misleading, however: the apparently autonomous individual will still need some help in order to reach a decision, such as the provision of information in a language which she can understand.⁶

At the moment, the test for capacity under the Mental Capacity Act 2005 operates as a cliff edge.⁷ Patients with capacity have an almost absolute right to refuse medical treatment 'for rational or irrational reasons or for no reason at all'.⁸ In contrast, for a patient who lacks capacity, decisions are taken for her, in her best interests, and, according to the statute, her wish to refuse treatment is simply one relevant factor. My goal in this article is to consider whether it might be possible to soften the capacity cliff edge by ensuring that the best interests decisions which flow from a finding of incapacity give greater weight to the views and preferences of the person who lacks capacity, where they matter, or did matter deeply to her. Of course, there might be other ways to soften the capacity cliff edge, for example by providing that the wishes of a patient who only just fails the capacity test should carry more weight than those of a patient who is minimally conscious. This, however, would fail to capture the fact that, before losing consciousness, the minimally conscious patient may have had values and beliefs that were profoundly important to her.

Jonathan Herring has argued that when the inherent jurisdiction is used to protect vulnerable but capacitous adults,⁹ it can be used to correct a different defect that results from the Mental Capacity Act's binary 'all or nothing' approach to capacity,¹⁰ 'by offering the potential for legal intervention when a person has capacity, but only just'.¹¹ The inherent jurisdiction, according to Jonathan Herring and Jesse

⁴ W. Martin, S. Michalowski, T. Jütten and M. Burch, 'Achieving CRPD Compliance: Is the Mental Capacity Act of England and Wales compatible with the UN Convention on the Rights of Persons with Disability? If not, what next?' (Essex Autonomy Project, 2014).

⁵ M. Gunn, 'The Meaning of Incapacity' (1994) 2 *Medical Law Review* 8-29.

⁶ On the fiction of the 'unencumbered, free, rational decision maker', see further J. Herring, *Vulnerable Adults and the Law* (Oxford University Press, 2016).

⁷ J. Herring, 'Losing It? Losing What? The Law and Dementia', (2009) 21 *Child and Family Law Quarterly* 3-29; J. Coggon, 'Mental Capacity Law, Autonomy, and best Interests: An Argument for Conceptual and Practical Clarity in the Court of Protection' (2016) 24 *Medical Law Review* 396-414.

⁸ *Re MB (An Adult: Medical Treatment)* [1997] 2 FLR 426, *per* Butler-Sloss LJ at [30]. See also *Re T* [1992] EWCA Civ 18 *per* Lord Donaldson MR at [3]: 'This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent'.

⁹ It should be noted that there are multiple other uses of the inherent jurisdiction, the scope of which was described in *Re B (Secure Accommodation: Inherent Jurisdiction) (No 1)* [2013] EWHC 4654 (Fam) at [20] as 'theoretically limitless'.

¹⁰ Herring, n 8 above, 56.

¹¹ *ibid*, 71.

Wall,¹² and the President of the Family Division,¹³ is an example of ‘judicial law-making’, which serves to soften the capacity cliff edge in order to recognise, controversially,¹⁴ that some adults who might pass the mental capacity test nevertheless need to be protected from abuse. My focus in this article is instead on adults who *fail* the statutory mental capacity test, but who have (or had) core values and preferences that matter deeply to them. For such patients, I argue that a different softening of the effects of the capacity cliff edge may be necessary in order to treat them with appropriate respect and dignity.

Of course, it could be argued that, in practice, the judiciary is perfectly capable of placing more weight on an incapacitated adult’s core values and beliefs. Indeed, we could point to the Mental Capacity Act itself and its application in the courts, discussed in more detail in the following section, in order to demonstrate that the current law is flexible enough to accommodate an explicitly patient-centred approach to best interests.¹⁵ Most medical decisions for people who lack capacity do not come before the courts, however, but are made instead by clinicians, with input from those close to the patient. In its post-legislative scrutiny of the Mental Capacity Act, the House of Lords Select Committee found that ‘especially in medical settings, the concept of best interests as defined by the Act was not well understood’.¹⁶ In particular, it found that: ‘Best interests decision-making is often not undertaken in the way set out in the Act: the wishes, thoughts and feelings of P are not routinely prioritised. Instead, clinical judgments or resource-led decision-making predominate’.¹⁷

And while there is evidence that the judiciary is increasingly willing to take seriously its duty to consider matters from the patient’s point of view, Lucy Series has pointed out that this is not universally the case,¹⁸ and that best interests decisions in which other considerations trump the patient’s wishes are as compatible with the statute as the more patient-focussed decisions discussed below.¹⁹ Certainly the Act itself does not direct decision-makers to give any priority to the wishes and beliefs of the person who lacks capacity (referred to in the statute as P). Nor is there any formal expectation that P will

¹² J. Herring and J. Wall, ‘Autonomy, capacity and vulnerable adults: filling the gaps in the Mental Capacity Act’ (2015) 35 *Legal Studies* 698-719.

¹³ J. Munby, ‘Protecting the Rights of Vulnerable and Incapacitous Adults—The Role of the Courts: An Example of Judicial Law Making’, [2014] 26 *Child and Family Law Quarterly* 64-77.

¹⁴ See, for example, M. Dunn, I. Clare, and A. Holland, ‘To Empower or To Protect? Constructing the ‘vulnerable adult’ in English Law and Public Policy’ (2008) 28 *Legal Studies* 234-53; J. Miles, ‘Family Abuse, Privacy and State Intervention’ [2011] 70 *Cambridge Law Journal* 31-34.

¹⁵ See, for example, *Aintree University Hospitals Foundation Trust v James* [2013] UKSC 67 at [45].

¹⁶ House of Lords Select Committee on the Mental Capacity Act 2005, Report of Session 2013-14 *Mental Capacity Act 2005: post-legislative scrutiny* (Parliament, 2014), para 92.

¹⁷ *ibid*, para 104.

¹⁸ L. Series, ‘The Place of Wishes and Feelings in Best Interests Decisions: *Wye Valley NHS Trust v Mr B*’ (2016) 79 *Modern Law Review* 1101-1115.

¹⁹ See, for example, *RB v Brighton and Hove City Council* [2014] EWCA Civ 561.

participate directly in any court proceedings in which her best interests are to be determined.²⁰ As Helen J Taylor has put it: ‘The MCA has drawn attention to the need for decision makers to consider a range of issues wider than the patient’s clinical interests, yet provides insufficient guidance on how the statutory principles should be applied in practice’.²¹ On the face of the statute, P’s wishes and beliefs are just one of any number of considerations that should be taken into account when determining what is in her best interests.

My purpose in this article is to consider the advantages and disadvantages of providing additional guidance to decision-makers in order to help them steer a path between taking seriously the wishes of people who lack capacity, while at the same time not abandoning patients who need help and support to their ‘autonomy’, where to do so might amount to neglect or ill-treatment. More specifically, this article will consider whether it might be possible essentially to formalise current best practice in the Court of Protection by deriving a series of rebuttable presumptions, or to put it less stridently, ‘starting points’,²² from existing statutory provisions and human rights instruments. But before coming to how this might work in practice, and the relative merits of structured versus unstructured discretion, it is first important to acknowledge that much more dramatic changes than the ones I advocate here have taken place in the courts over the course of the last 28 years.

3. From *Re F* to *Aintree* and beyond

It is worth reminding ourselves that, while medical treatment had been provided to patients who lacked capacity for hundreds of years, until 1989 the basis for its legality was opaque.²³ As Lord Goff pointed out in *Re F (Mental Patient: Sterilisation)*:²⁴

²⁰ Indeed, in a non-medical case, *YLA v PM, MZ* [2013] EWHC 4020 (COP) Parker J specifically declined an invitation to meet P in order to ascertain her wishes and feelings, explaining at [34] that ‘I was particularly concerned ... that I was being asked to form my own assessment of the strength of her wishes and feelings: and indeed capacity. In children’s cases the court sees the child for the purpose of allowing wishes and feelings to be expressed and to allow the child to feel part of the proceedings: the meeting is not to be used for gathering evidence’.

²¹ H.J. Taylor, ‘What are “best interests”? A critical evaluation of “best interests” decision-making in clinical practice’ (2016) 24 *Medical Law Review* 176-205.

²² If these presumptions were alternatively framed as ‘starting points’, derogation would be possible but, as with a rebuttable presumption, this would require specific and compelling justification.

²³ Two years earlier, in *T v T* [1988] Fam 52, doctors had sought legal protection for their decision to terminate a mentally incapacitated woman’s pregnancy and sterilise her at the same time. Wood J granted the declaration, on the grounds that ‘a medical adviser is justified in taking such steps as good medical practice “demands”’ (at 68), despite ‘the fact that the operative procedures proposed are prima facie acts of trespass’ (at 67), to which no one, not even the court, could give consent.

²⁴ n 1 above.

The argument of counsel revealed the startling fact that there is no English authority on the question whether as a matter of common law (and if so in what circumstances) medical treatment can lawfully be given to a person who is disabled by mental incapacity from consenting to it.²⁵

The previous year, in *Re B (A Minor) (Wardship: Sterilisation)*,²⁶ this uncertainty had lent urgency to the court's decision to authorise B's sterilisation before her 18th birthday:

It is clearly to the interest of the ward that this matter be decided now and without further delay. We should be no wiser in 12 months' time than we are now and it would be doubtful then what legal courses would be open in the circumstances.²⁷

Then in *Re F (Mental Patient: Sterilisation)*,²⁸ the House of Lords found a solution to the 'startling' absence of legal authority in the doctrine of necessity, and declared that it would be in her best interests, and therefore lawful, to sterilise a 36-year-old woman, who had 'the mental capacity of a child of four to five'.²⁹ According to Lord Bridge, it was 'axiomatic that treatment which is necessary to preserve the life, health or well being of the patient may lawfully be given without consent'.³⁰ But if 'necessity' only covered the provision of treatment where a person's life was at risk, 'many of those unfortunate enough to be deprived of the capacity to make or communicate rational decisions by accident, illness or unsoundness of mind might be deprived of treatment which it would be entirely beneficial for them to receive'.³¹ 'Necessity' was thus extended to include treatment that was provided in the person's best interests.

This common law principle survived until it was codified in section 1(5) of the Mental Capacity Act 2005: 'an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests'. The meaning of 'best interests' had changed significantly between 1989 and 2005, however. In 1989, there was no mention of the patient's views, values or beliefs. Instead, when deciding what medical treatment was in a patient's best interests, the test was what *other doctors* would consider to be in her best interests: that is, the *Bolam* test applied.³² The right to be treated in one's best interests was therefore conflated with the rather minimal requirement that one should receive non-negligent medical care. Lord Goff had acknowledged that, in working out what was

²⁵ *ibid* at 71.

²⁶ [1988] AC 199.

²⁷ *ibid per* Lord Hailsham at 203.

²⁸ n 1 above.

²⁹ *ibid per* Lord Brandon, at 53. For criticism of the infantilising effects of describing adult women in terms of their mental age, see R. Lee and D. Morgan, 'Sterilisation and mental handicap: sapping the strength of the state?' (1988) 15 *Journal of law and society* 229-246.

³⁰ *ibid per* Lord Bridge, at 52.

³¹ *ibid per* Lord Bridge, at 52.

³² *ibid per* Lord Brandon, at 68.

in a person's best interests, it would sometimes be necessary to consult others, but not, it appears, the person herself:

No doubt, in practice, a decision may involve others besides the doctor. It must surely be good practice to consult relatives and others who are concerned with the care of the patient. Sometimes, of course, consultation with a specialist or specialists will be required; and in others, especially where the decision involves more than a purely medical opinion, an inter-disciplinary team will in practice participate in the decision.³³

In 1989, it was taken for granted that an incapacitated adult who could not communicate through speech, but who could 'indicate what she likes or dislikes',³⁴ and was held capable of having a sexual relationship that was 'entirely voluntary',³⁵ would have nothing to contribute to a decision about her medical treatment.

Over the course of the next sixteen years, this objective and paternalistic approach to determining what is in a patient's best interests was supplemented by the growing recognition that the patient might have a view about her treatment, or relevant values and beliefs, that ought to be taken into account. Just four years later, in *Airedale NHS Trust v Bland*,³⁶ although the 'substituted judgment test', used in the US, which asks what decision the patient would make if she were able to take the decision for herself, was briskly dismissed by Lord Goff, who did 'not consider that any such test forms part of English law',³⁷ Hoffmann LJ in the Court of Appeal had been more open to the idea that the patient's wishes might be relevant to what is in her best interests:

The patient's best interests would normally also include having respect paid to what seems most likely to have been his own views on the subject. To this extent I think that what the American courts have called 'substituted judgment' may be subsumed within the English concept of best interests.³⁸

By the time the Mental Capacity Act 2005 was passed, it was widely acknowledged that determining what is in a patient's 'best interests' was no longer a purely objective exercise, but as the Law Commission report had put it, contained a 'strong element of substituted judgment'.³⁹ In 2005, for

³³ *ibid* at 78.

³⁴ *ibid per* Lord Brandon, at 53.

³⁵ *ibid*.

³⁶ [1993] AC 789.

³⁷ *ibid* at 872. See, for example, *Cruzan v Director, Missouri Department of Health* 497 US 261 (1990).

³⁸ *ibid* at 833.

³⁹ Law Commission, *Report on Mental Incapacity* Law Com No 231 (Law Commission, 1995), para 3.25.

example, in *An NHS Trust v X*,⁴⁰ Waller LJ made it clear that the patient's views were 'highly material', albeit 'not the governing factors when considering best interests'.⁴¹

The equation of 'best interests' and the *Bolam* test, described subsequently by Sir James Munby P as 'unfortunate' and 'potentially disastrous',⁴² had also been superseded. Not only did it disregard the patient's perspective, but also reasonable doctors might disagree about what treatment would be best for a patient. In *Re NK*,⁴³ for example, the medical evidence led to the unhelpful conclusion that it would be lawful, as in her best interests, for NK to be sterilised, while it would also be lawful, in her best interests, *not* to be sterilised.⁴⁴ As Dame Elizabeth Butler-Sloss P put it in *Re S (Adult Patient: Sterilisation: Patient's Best Interests)*,⁴⁵ 'the best interests test ought, logically, to give only one answer'.⁴⁶

As well as codifying the best interests test, section 4 of Mental Capacity Act 2005 set out a non-exhaustive checklist of factors that decision-makers must consider when deciding what is in a person's best interests.⁴⁷ In this list, while the wishes, values and beliefs of P are important, they do not have primacy over other considerations. This was deliberate. The then government's view was that 'prioritisation of the factors would unnecessarily fetter their operation in the many and varied circumstances in which they might fall to be applied'.⁴⁸ In an early non-medical case HHJ Marshall QC had suggested that, where P's wishes are not 'irrational', 'impracticable' or 'irresponsible', there might be 'a presumption in favour of implementing those wishes, unless there is some potential sufficiently detrimental effect for P of doing so which outweighs this'.⁴⁹ More commonly, however, until the judgment of the Supreme Court in *Aintree University Hospitals Foundation Trust v James*,⁵⁰ the courts would consider 'the extent to which P's wishes and feelings, if given effect to, can properly be accommodated within the court's overall assessment of what is in her best interests'.⁵¹

In practice, this meant that where the patient's life was potentially at stake, her wishes might be trumped by concern for the preservation of life. In *Re M (Adult Patient) (Minimally Conscious State:*

⁴⁰ [2005] EWCA Civ 1145.

⁴¹ *ibid* at [59].

⁴² Munby, n 15 above.

⁴³ (1990) 4 April (unreported), discussed in Munby, n 15 above.

⁴⁴ Of course, application of the least restrictive alternative principle might lead to the conclusion that NK should not be sterilised.

⁴⁵ [2001] Fam 15.

⁴⁶ *ibid* at 27.

⁴⁷ Section 4.

⁴⁸ *Government Response to the Scrutiny Committee's Report on the Draft Mental Incapacity Bill* Cm 6121 (2004).

⁴⁹ *Re S and S (Protected Persons); C v V* [2008] EWHC B16 (Fam) at [57].

⁵⁰ n 17 above.

⁵¹ per Munby J in *Re M (Statutory Will)* [2009] EWHC 2525 (Fam) at [35], quoted, for example, in *A London Local Authority v JH* [2011] EWCOP 2420 and *An NHS Trust v DE* [2013] EWHC 2562 (Fam).

Withdrawal of Treatment),⁵² for example, Baker J explained that ‘The first principle is the right to life... It carries very great weight in any balancing exercise’.⁵³ Because it was impossible to be certain how M felt about her life in a minimally conscious state, and despite clear statements from her partner and family about what they thought M would have wanted, Baker J held that ‘the court must be particularly cautious about attaching significant weight to statements she made before her collapse’.⁵⁴ Instead, Baker J concluded that ‘the importance of preserving life is the decisive factor in this case’.⁵⁵

Then in *Aintree University Hospitals Foundation Trust v James*,⁵⁶ Lady Hale, with whom the other Justices agreed, made a small but significant change of emphasis in describing the relevance of the patient’s wishes. Lady Hale did not describe the patient’s perspective as simply one material factor, to be ‘accommodated’ within an objective assessment of what was in his best interests. Instead, ‘the purpose of the best interests test is to consider matters from the patient’s point of view’.⁵⁷ Lady Hale was careful to stress that that does not necessarily mean that the patient’s view must prevail, because, just like patients with capacity, ‘we cannot always have what we want’.⁵⁸ But, if it is ‘possible to ascertain the patient’s wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being’.⁵⁹

Post-*Aintree*, therefore, if the patient’s wishes can be ascertained, they should be central to the decision as to what is in her best interests. And in cases that have followed *Aintree*, judges sitting in the Court of Protection have been emboldened to take P’s wishes very seriously indeed, even when they are contrary to an ‘objective’ view of what is in P’s clinical best interests. For example, in several recent cases, the ‘preservation of life’ has not operated as a trumping principle, when put into the balance with the patient’s wishes. Rather, there have been times when the courts have, in practice, respected refusals of life-prolonging treatment, in order that the lives of adults who lack capacity might come to an end in a way that is consistent with their core values and beliefs.

⁵² [2011] EWHC 2443.

⁵³ *ibid* at [222].

⁵⁴ *ibid* at [228].

⁵⁵ *ibid* at [249]. See also *A Local Authority v E* [2012] EWHC 1639, a case involving a 32-year-old woman with severe anorexia, in which Peter Jackson J was faced with the need to strike a balance ‘between the weight objectively to be given to life on one hand and to personal independence on the other’ (at [5]). In this case, the preservation of E’s life took priority over her wish to refuse artificial feeding (at [137]).

⁵⁶ n 17 above.

⁵⁷ *ibid* at [45].

⁵⁸ *ibid* at [45].

⁵⁹ *ibid* at [45].

In *Wye Valley NHS Trust v B*,⁶⁰ for example, a case involving a man who lacked capacity and who would be likely to die if his leg was not amputated, Peter Jackson J explained that ‘the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important’.⁶¹ In this case, it would not be in Mr B’s interests ‘to take away his little remaining independence and dignity in order to replace it with a future for which he understandably has no appetite and which could only be achieved after a traumatic and uncertain struggle that he and no one else would have to endure’. Peter Jackson J therefore decided that, notwithstanding his inability to make the decision for himself, Mr B’s wish not to have his leg amputated should be respected.

More recently, in *Briggs v Briggs*,⁶² 10 months after Mr Briggs had sustained serious brain injuries in a road traffic accident, and despite the view of his treating team that he should be transferred to a rehabilitation unit, Charles J was clear that ‘if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in favour of preserving life’.⁶³ Charles J was of the view that Baker J’s warning in *Re M* that the court should be ‘particularly cautious about attaching significant weight’ to M’s previously expressed wishes ‘runs counter to the holistic approach that the Supreme Court confirms is to be taken to enabling P to do what he would have wanted if of full capacity’.⁶⁴ Instead, Charles J took seriously the views of members of Mr Briggs’s family that he ‘would regard his present situation as horrible and one that he would not wish to continue’.⁶⁵ As a result, he concluded that, if Mr Briggs had had capacity, he would ‘not have consented to further CANH [clinically assisted nutrition and hydration] treatment’, and therefore ‘his best interests are best promoted by the court not giving that consent on his behalf’.⁶⁶

In addition to giving considerable weight to the patient’s views, even where her life is potentially at stake, another feature of recent cases in the Court of Protection is the lengths to which the judges have gone in order to ‘consider matters from the patient’s point of view’,⁶⁷ including, but not limited to meeting P in order to hear her views directly.⁶⁸ For example, in *Wye Valley NHS Trust v B*,⁶⁹ Peter

⁶⁰ [2015] EWCOP 60. For further discussion, see Series n 20 above.

⁶¹ *ibid* at [11].

⁶² [2016] EWCOP 53.

⁶³ *ibid* at [62].

⁶⁴ *ibid* at [80].

⁶⁵ *ibid* at [111].

⁶⁶ *ibid* at [129].

⁶⁷ *per* Lady Hale in *Aintree*, n 17 above at [45].

⁶⁸ See also *Betsi Cadwaladr University Local Health Board v W* [2016] EWCOP 13 at [33], in which Peter Jackson J commented upon having met a patient about whom a potentially life and death decision had to be taken, saying that he had ‘valued the opportunity to meet her and to understand her point of view as clearly as possible’.

Jackson J set out in his judgment the reasons why it had been important for him to visit Mr B in hospital. First, he had ‘obtained a deeper understanding of Mr B’s personality and view of the world, supplementing and illuminating the earlier reports’.⁷⁰ Secondly, ‘Mr B seemed glad to have the opportunity to get his point of view across. To whatever small degree, the meeting may have helped him to understand something of the process and to make sense of whatever decision was then made’.⁷¹ And, thirdly, enabling Mr B to ‘have the fullest opportunity to get his point across’ was beneficial for the nursing staff, who would have to care for him through ‘what will undoubtedly be a difficult time’.⁷²

Prompted in part by Peter Jackson J’s account of the benefits he had derived from visiting Mr B, Mostyn J decided that he too would meet the patient whose treatment was at stake in *A Hospital NHS Trust v CD*.⁷³ Once again, he explained the value of hearing directly from CD:

the reason it was enlightening for me was that the person I met was different in many respects to the person described in the papers. CD was engaging and polite. She was articulate. She was amusing. She listened carefully to questions and answered them equally carefully. True, there were comments that suggested powerful delusional forces; and Dr FH explained that she was heavily medicated. But even so, the person I met was a world away from the violent sociopath described in the papers.⁷⁴

Even when the judge has not met the patient, post-*Aintree*, he or she will invariably explain, as MacDonald J did in *Cambridge University Hospitals NHS Foundation Trust v BF*,⁷⁵ that: ‘I have done the best I can to consider the position from BF’s point of view’.⁷⁶

It is hard to believe that fewer than three decades separate these empathetic judicial accounts of P, and her values and wishes, and the blunt paternalism of *Re F (Mental Patient: Sterilisation)*,⁷⁷ in which the House of Lords was concerned to devise a mechanism which would enable a doctor lawfully to give an ‘incompetent’ patient treatment in her best interests, judged objectively by what the reasonable doctor would do in the circumstances. But while the judiciary has been increasingly willing to take seriously the past and present wishes, values and beliefs of patients who lack capacity, the same cannot be said of healthcare professionals, who are responsible for making the vast majority of best interests decisions under the Act. And while the judiciary is to be commended for its efforts to understand P’s point of

⁶⁹ n 67 above.

⁷⁰ *ibid* at [18].

⁷¹ *ibid* at [18].

⁷² *ibid* at [18].

⁷³ [2015] EWCOP 74.

⁷⁴ *ibid* at [31].

⁷⁵ [2016] EWCOP 26.

⁷⁶ *ibid* at [65].

⁷⁷ n 1 above.

view, it is striking there is no formal requirement to hear directly from P when deciding what should be done, or not done to her body.

As a result, in what follows I propose the introduction of three new presumptions, or starting points. First, an initial presumption would involve no more than a modest change to the Court of Protection rules, namely that when a decision about P's medical treatment comes before the Court of Protection, the judge should, where reasonably practicable, meet P in order to hear from her directly. Secondly, and applying to all decision-makers under the Act, there could be a new presumption, set out either in the statute or, more realistically, in the Code of Practice, that, if P wishes to refuse a medical intervention, her refusal should be respected, unless to do so would result in significant harm to P. Thirdly, where there *is* a risk of significant harm to P from respecting her wishes, the presumption (or starting point) might be that her refusal of unwanted medical intervention should be respected, if it is grounded in her core values and beliefs, that is, in views that are, or were, of profound importance to P. Just as with patients who have capacity, it is only refusals of medical treatment that could be decisive under this scheme; for all patients, capacitous or not, their desire to receive a particular treatment is relevant but not determinative.⁷⁸

To take a simple example, imagine that P has been a lifelong adherent of the Jehovah's Witness faith, but that she has not executed an advance decision refusing blood products. P now lacks capacity and expresses vehemently to the judge her unwillingness to undergo a blood transfusion. In this case, P's wishes can be ascertained, and if given primacy, might be likely to cause her significant physical harm. Since those wishes represent P's deeply held values and beliefs, there might nevertheless be a good reason to respect them.⁷⁹

Of course, most decisions are not this straightforward or clear-cut, and I do not mean to suggest that these presumptions would convert sensitive, fact-specific judgments about where P's best interests lie into the formulaic application of an inflexible algorithm. Clearly there will still be important and difficult judgments to make about when a risk of harm is significant, and what counts as a profoundly important belief. In addition, it may be necessary to consider whether there are circumstances which justify departing from the rebuttable presumption in the particular case. But a presumption that P is heard in court proceedings, and that, in certain circumstances, her wishes should be decisive, would help to ensure that current best practice in the Court of Protection is the starting point whenever a doctor or

⁷⁸ See, for example, the judgment of the Court of Appeal in *R (on the application of Burke) v General Medical Council* [2005] EWCA Civ 1003 at [55]: 'a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient's clinical needs'.

⁷⁹ Coggon, n 9 above.

court is faced with an incapacitated adult who has a view about her medical treatment that matters (or did matter) deeply to her.

4. P's Involvement in Court Proceedings

The Court of Protection is involved in a tiny minority of medical decisions taken on behalf of adults who lack capacity. Where treatment is routine, and there is no dispute, decisions are taken by clinicians in what they consider to be P's best interests. The Mental Capacity Act Code of Practice and the Court of Protection's Practice Direction 9E set out the limited circumstances in which it is appropriate to seek a declaration from the Court of Protection before proceeding with medical treatment. These include the proposed withholding of clinically assisted nutrition and hydration;⁸⁰ live organ donation; non-therapeutic sterilisation, and 'all other cases where there is a doubt or dispute about whether a particular treatment will be in a person's best interests'.⁸¹ Also 'likely to be referred to the court' are cases 'where there are otherwise irresolvable conflicts between healthcare staff, or between staff and family members',⁸² or where 'it is unclear whether proposed serious and/or invasive medical treatment is likely to be in the best interests of the person who lacks capacity to consent'.⁸³

Although the local NHS body should refer cases where it is not clear whether a procedure is in P's best interests, it is, of course, possible that the professionals responsible for P's care will be confident in their best interests decision, and, if P's relatives agree with them, there may be no lack of clarity, and no apparent dispute, and hence no referral. In their evidence to the House of Lords Select Committee, Phil Fennell and Lucy Series pointed out the peculiarity of this: 'surely, under the ECHR [European Convention on Human Rights], a person's rights to access justice to assert their capacity cannot hinge on something so arbitrary as whether or not their relations and professionals have fallen out?'⁸⁴

⁸⁰ Although note that in *Director of Legal Aid Casework v Briggs* [2017] EWCA Civ 1169, the Court of Appeal was of the view that, where there was no dispute, there is no legal requirement to bring to court cases involving the withdrawal of CANH from PVS and MCS patients. At the moment, therefore, there is conflicting authority on this point. See further, A. Ruck Keene, 'Procedure, practice and legal requirements: a commentary on "Why I wrote my advance decision"' (2017) 43 *Journal of Medical Ethics* 435-438.

⁸¹ Mental Capacity Act 2005 Code of Practice, para 8.18.

⁸² *ibid*, para 8.23.

⁸³ *ibid*, para 8.24. Para 3 of Practice Direction 9E, which supplements the Court of Protection Rules 2007, sets out the procedure to be followed when an application to the Court of Protection 'concerns serious medical treatment in relation to P'. It specifies that medical treatment should be considered 'serious' where 'there is a fine balance between its benefits to P and the burdens and risks it is likely to entail for him', or where 'the treatment, procedure or investigation proposed would be likely to involve serious consequences for P', such as 'serious and prolonged pain, distress or side effects', or 'a serious impact on P's future life choices'.

⁸⁴ House of Lords Select Committee on the Mental Capacity Act 2005, n 18 above, para 235.

It is striking that the fact that P objects to the treatment is not set out in the Code of Practice or in Practice Direction 9E as a separate justification for seeking court approval, although in *NHS Trust & Ors v FG*,⁸⁵ Keehan J agreed with the Official Solicitor that ‘a serious dispute as to what obstetric care is in P’s best interests ... between the clinicians and P’ was one of a number of circumstances in which Trusts should apply to the Court of Protection in order to obtain orders relating to P’s obstetric care.⁸⁶

Once a case does come before the Court of Protection, although there has recently been a shift in approach, the court’s ‘original practices and procedures were not built upon the presumption that P would routinely participate directly in cases that are about them’.⁸⁷ It is, as Series et al note, somewhat surprising that ‘a jurisdiction wholly devoted to matters concerning people with mental disabilities’ had until recently ‘given no systematic consideration to the special measures and reasonable adjustments that would be needed to facilitate the participation of P’.⁸⁸ And indeed there have been cases in which P has not just not participated, but has not even been informed that the hearing was taking place. In *Re AA (Compulsorily Detained Patient: Elective Caesarean)*,⁸⁹ for example, there was no intention to tell the pregnant woman about the existence of an order that a caesarean section should be performed upon her, ‘under sedation’ and, if necessary ‘with the use of reasonable restraint’, ‘until after the medical procedure ... has been completed’.⁹⁰

It could be argued that a failure to hear directly from P when making a decision about her medical treatment is at odds with section 4(4) of the Mental Capacity Act 2005, which provides that the person making the determination about what is in P’s best interests – which, in the Court of Protection, is the judge – ‘must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.’

Might it also be possible to argue that when a decision about the medical treatment of a person who lacks capacity comes before a court, Article 6 of the ECHR requires her to have access to ‘a fair and public hearing ... by an independent and impartial tribunal’? A ‘fair hearing’ would ordinarily mean that she is entitled to be heard in person by that tribunal. In the European Court of Human Rights

⁸⁵ [2014] EWCOP 30.

⁸⁶ *ibid* at [103]. According to Keehan J, ‘A decision to compel a mother, who would otherwise wish to have as natural a birth as possible, to undergo treatment which amounts to SMT [serious medical treatment] is a very serious interference with her human rights as protected by the ECHR. In my judgment such decisions in the case of a P should be brought before the court for permission to undertake the same’ (at [113]).

⁸⁷ L. Series, P. Fennell and J. Doughty, *The Participation of P in Welfare Cases in the Court of Protection* (Cardiff University, 2017), 25.

⁸⁸ *ibid*, 15.

⁸⁹ [2012] EWHC 4378 (COP).

⁹⁰ As set out in para 5 of the declaration of the Court.

(ECtHR)’s jurisprudence on Article 6, as applied to people with mental disabilities, it has said that it will ‘read across’ from Article 5(1) of the ECHR,⁹¹ and the principle that where a person’s freedom is at stake, ‘a person of unsound mind must be allowed to be heard either in person or, where necessary, through some form of representation’.⁹² In *X and Y v Croatia*,⁹³ for example, the ECtHR explained that ‘judges adopting decisions with serious consequences for a person’s private life, such as those entailed by divesting someone of legal capacity, should in principle also have personal contact with those persons’.⁹⁴ According to Series et al, this personal contact is necessary both in order to protect the person’s dignity – there is a ‘fundamental right to meet judges taking decisions with serious consequences for a person’s life’ – and in order to ensure that the court has sufficient evidence on which to base its decision.⁹⁵

In 2015 in *Re X (Court of Protection Practice)*,⁹⁶ in *obiter* comments,⁹⁷ the Court of Appeal pointed out that, in proceedings to authorise a deprivation of liberty, ‘it is generally considered indispensable in this country for the person whose liberty is at stake automatically to be a party to the proceedings in which the issue is to be decided’.⁹⁸ If P must be joined as a party, when her liberty is at stake, it would be difficult to justify the conclusion that giving medical treatment to P against her wishes is less intrusive, such that joining her as a party is unnecessary.⁹⁹ In some cases, non-consensual medical treatment will be more invasive and intrusive than preventing P from leaving a care home. A locked door may restrict a person’s liberty, but pinning someone down in order to give her an injection violates her bodily integrity as well.

Within the last two years, there is evidence of a change in approach within the Court of Protection. It could be argued that the most recent Court of Protection Rules and Practice Directions go some considerable way towards facilitating P’s direct involvement in court proceedings.¹⁰⁰ Under Rule 90, P is entitled to attend any hearing in the Court of Protection, and a new Rule 3A ‘requires the court in every case to consider whether it should make one, or more, of a number of possible directions for

⁹¹ *AN v Lithuania* [2016] ECHR 462.

⁹² *Shtukaturv v Russia* (2012) 54 EHRR 2 at [71].

⁹³ [2011] ECHR 1835.

⁹⁴ *ibid* at [84].

⁹⁵ Series et al, above n 102, 51.

⁹⁶ [2015] EWCA Civ 599.

⁹⁷ Following the Supreme Court’s decision in *Cheshire West and Chester Council v P* [2014] UKSC 19, there had been a massive increase in the number of Deprivation of Liberty Safeguards (DoLS) cases coming before the Court of Protection, and the President of the Family Division had therefore attempted to devise a ‘streamlined’ process, through which some DoLS cases could be ‘properly dealt with on the papers and without an oral hearing’. The Court of Appeal found that the President did not have the jurisdiction to develop a new rule of procedure in order to enable Deprivation of Liberty Safeguards cases to be dealt with on the papers.

⁹⁸ Above n 111, *per* Black LJ at [86].

⁹⁹ In *Zagidulina v Russia* [2013] ECHR 398, the ECtHR maintained that: ‘Taking into consideration the applicant’s clear and undisputed refusal to undergo any treatment and the domestic courts’ awareness of this fact ... the need to ensure the applicant’s right to be heard was ever more pressing’ (at [62]).

¹⁰⁰ Practice Direction 2A.

securing P's participation', with one possible direction being 'giving P the opportunity to address the judge directly or indirectly'.¹⁰¹

Practice Direction 2A acknowledges that enabling P to address the judge directly is not without costs.¹⁰² There may be more obstacles to P's participation in court proceedings than a simple failure to make hearing from her directly the default option. According to Anna Lawson and Eilionór Flynn, patients also commonly encounter 'inadequate legal information and advice; insufficient resources; inaccessible architectural design; inaccessible information or communication methods in court'.¹⁰³ Effective patient participation might also in practice require the provision of, and funding for an advocate, who can help the patient to participate, or speak on her behalf. Although legal aid is in theory available for health and welfare decisions in the Court of Protection, means testing means that, in practice, relatively few people are eligible.¹⁰⁴ Of course, the Official Solicitor will often have been appointed to act as P's litigation friend, but he has a duty to act in P's best interests, rather than to simply represent her views. In practice, then, in many welfare cases in the Court of Protection, there is nobody to speak on P's behalf.

For patients with severe cognitive disabilities, ascertaining their views may be time-consuming and challenging. Additional training may be necessary in order to enable judges and other court staff to understand and engage constructively with a patient who finds communication difficult.¹⁰⁵ As Mind explained in their evidence to the House of Lords Select Committee: 'To assess, engage and empower a person who may lack capacity can be resource intensive. It may require help from speech therapists or occupational therapists or for more time to be devoted to that person by the care staff or clinical team supporting them'.¹⁰⁶

If the judge can only hear directly from P by visiting her in a hospital or home, this may delay proceedings and have further resource implications. It is also possible that what the patient says may complicate decision-making, perhaps because her present wishes appear to contradict her past beliefs.¹⁰⁷ Furthermore, the judge might meet the patient when she is having a particularly good or bad day (although it should be admitted that this may be the case whenever a judge hears directly from anyone). In any event, the patient's account of her preferences will not be the only evidence before the judge, and

¹⁰¹ Rule 3A(2)(d).

¹⁰² Practice Direction 2A, para 1.

¹⁰³ A. Lawson and E. Flynn, 'Disability and Access to Justice in the European Union: Implications of the UN Convention on the Rights of Persons with Disabilities' (2013) 4 *European Yearbook of Disability Law* 7-44.

¹⁰⁴ See, for example, *Bournemouth Borough Council v BS* [2015] EWCOP 39 at [5].

¹⁰⁵ Series et al, n 102 above.

¹⁰⁶ House of Lords Select Committee on the Mental Capacity Act 2005, n 18 above, para 18.

¹⁰⁷ M. Donnelly, 'Best interests, patient participation and the Mental Capacity Act 2005' (2009) 17 *Medical Law Review* 1-29.

any interpretative difficulties presented by having met P may be, I would suggest, outweighed by the importance of not excluding patients who lack capacity from the principle, now invoked in a variety of healthcare contexts, ‘no decision about me, without me’.¹⁰⁸

Under section 20 of the Equality Act 2010, the Courts and Tribunals Service is under a duty to make ‘reasonable adjustments’ in order to avoid any substantial disadvantage that a disabled person may face in accessing the court on account of their disability. And further support for a duty to make reasonable accommodations in order to facilitate P’s participation within any court proceedings in which her medical treatment is at stake might be found in Article 13(1) of the UN Convention on the Rights of Persons with Disabilities (CRPD):

States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings.¹⁰⁹

In 2016, the Vice-President of the Court of Protection, introduced practice guidance on *Facilitating the participation of P and vulnerable persons in CoP proceedings*,¹¹⁰ which goes into considerable detail on the steps that may need to be taken to facilitate P’s participation in court proceedings. For example, consideration may have to be given to practical matters like toilet facilities, and to questions like: ‘Where and how will the Court’s decision be communicated to P?’¹¹¹ It is therefore clear that the judiciary is increasingly willing to take steps proactively to involve P directly in proceedings in which her medical treatment is at stake. As a result, it would be a small step to amend Rule 3A in order to provide that, in keeping with the principle that P should always be at the centre of any decision about her medical treatment, the starting point, or presumption should be that the court should hear from P directly, unless to do so would not be reasonably practicable.

¹⁰⁸ Department of Health, *Liberating the NHS: No decision about me, without me* (DH, 2012); A. Coulter and A. Collin, *Making Shared Decision-Making a Reality: No decision about me, without me* (Kings Fund, 2011).

¹⁰⁹ Cited in support of a duty to make reasonable adjustments by the Employment Appeal Tribunal in *J W Rackham v NHS Professionals Ltd* [2015] UKEAT 0110_15_1612

¹¹⁰ Mr Justice Charles, ‘Facilitating participation of ‘P’ and vulnerable persons in Court of Protection proceedings’ (2016) https://www.dropbox.com/s/211fmadsfwkrnlm/Practice_Guidance_Vulnerable_Persons.pdf?dl=0 (last accessed 4 August 2017).

¹¹¹ *ibid.* Following the case of *A County Council v AB & Ors (Participation of P in Proceedings)* [2016] EWCOP 41, AB’s solicitor described the extensive steps that were taken to ensure that AB understood what was happening and that the environment was as comfortable and non-threatening as possible. For example, photographs were taken ‘of the judge, the courtroom and all the lawyers involved in the proceedings to explain to P the physical location and the identity of all involved in advance of the hearing’, and arrangements were made for ‘P to be supported by staff regarding personal care, and ensuring mobile hoists were provided for P in both locations for care’. See further <https://courtsofprotectionhandbook.com/2016/09/30/guest-post-facilitating-participation-of-p-in-court-of-protection-proceedings/> (last accessed 4 August 2017).

5. Article 8 and the right to have one's wishes given appropriate weight

It is axiomatic that Article 8 of the European Convention on Human Rights – the right to respect for private and family life – incorporates, for adults who have capacity, a broad right to self-determination.¹¹² As Lord Hughes put it in *Nicklinson v Ministry of Justice*: ‘The reach of article 8 can now be seen to be extensive’.¹¹³ If we consider David Feldman’s explanation of why treatment against one’s wishes represents an interference with the human rights of patients with capacity, it is by no means self-evident that adults who lack capacity should be treated as an exception:

Being subjected to treatment, especially invasive treatment, without one’s consent is calculated to threaten one’s sense of one’s own worth and the feeling of being valued by others. How valuable can a person be, one might ask, if others are prepared to do things to him which remove from him any control over his own destiny? What could be less compatible with one’s dignity than being treated as a person to whom such a thing might be done lawfully and properly?¹¹⁴

Certainly nothing in Article 8 requires respect for a patient’s refusal of unwanted medical treatment to be subject to a mental capacity cliff edge.¹¹⁵ Rather, for incapacitated patients too, ‘non-consensual treatment can be seen as interfering with their dignity, in that the patient may both feel demeaned and be regarded by others as being subject to demeaning domination by the decision-makers, whether medical or judicial’.¹¹⁶ Although in other contexts, ‘dignity’ has been accused of being a rather vague and slippery concept,¹¹⁷ here it captures the idea that a person is ‘entitled to give an account of herself (and of the way in which she is regulating her actions and organising her life), an account that others are to pay attention to’.¹¹⁸

A central reason for deferring to a person’s view about what treatment is in her best interests is that we cannot experience life from another person’s point of view.¹¹⁹ As Kim Atkins has explained

¹¹² See, for example, *Montgomery v Lanarkshire* [2015] UKSC 53, *per* Lords Kerr and Reid at [80] and *Pretty v UK* (2002) 35 EHRR 1. For discussion, see S. Wheatley, ‘Human rights and human dignity in the resolution of certain ethical questions in biomedicine’ (2000) 3 *European Human Rights Law Review* 312-325.

¹¹³ [2014] UKSC 38 at [263].

¹¹⁴ D. Feldman, ‘Human Dignity as a Legal Value: Part II’ (2000) *Public Law* 61-76. See also D. Feldman, ‘The Developing Scope of Article 8 of the European Convention on Human Rights’ (1997) 3 *European Human Rights Law Review* 265-274.

¹¹⁵ Richardson, n 3 above.

¹¹⁶ Feldman (2000) n 129 above.

¹¹⁷ See, for example, C. McCrudden, ‘Human Dignity in Human Rights Interpretation’ (2008) 19 *European Journal of International Law* 655-724 and R. Macklin, ‘Dignity is a useless concept: it means no more than respect for persons or their autonomy’ (2003) 327 *British Medical Journal* 1419.

¹¹⁸ J. Waldron, ‘How law protects dignity’ (2012) 71 *Cambridge Law Journal* 200-222.

¹¹⁹ T. Nagel, ‘What is it like to be a bat?’ (1974) 83 *The Philosophical Review* 435-450.

If we accept that the subjective character of experience is irreducible and that it is grounded in the particularity of our points of view, then we are bound to realize that our respect for each other's differences and autonomy embodies a respect for the particularity of each other's points of view.¹²⁰

Regardless of whether another person has, or does not have capacity, we cannot know 'what it is like to be the other, or to be in her situation'.¹²¹ This reason for taking seriously a person's account of themselves, and their preferences, is not capacity-specific. None of us knows what it is like to lead another's life, and that is the case irrespective of whether or not that person has the legal ability to give a valid consent to medical treatment. When a patient lacks the capacity to consent to an act which would be tortious in the absence of consent, the Mental Capacity Act provides a solution, namely that it is lawful to provide treatment in her best interests. But it would be a mistake to conflate a mechanism through which someone can be treated lawfully, despite her inability to consent, with the removal of her interest in having her views about what is to be done to her body treated with respect.¹²²

Accepting that there are times when decisions have to be made on behalf of someone who lacks capacity does not mean that her voice thereby becomes irrelevant. One of the most frightening aspects of the loss of capacity through conditions such as dementia is the feeling that one is no longer treated as someone of value.¹²³ As Catriona MacKenzie has argued, healthcare professionals should be under an obligation to recognise each patient's humanity, 'that is, to treat her as *someone*, with a conception of herself and for whom certain things matter' (emphasis in original).¹²⁴ Preserving a patient's sense that she is a person whose views count is an important way of treating her as a subject,¹²⁵ rather than as an object to whom things can be done without asking first. Returning to *Re F (Mental Patient: Sterilisation)*,¹²⁶ it is clear that F was the object of the proceedings, rather than their subject. She is present in the judgment not as a person with a history, a biography and a sense of self, but as a clinical and legal dilemma to be resolved by others.

Perhaps no one thought to seek F's reaction to the prospect of sterilisation because she was unable to communicate through speech. But an inability to speak does not mean that someone has 'nothing to tell us'.¹²⁷ Rather as those who care for non-verbal children and adults know, they may be

¹²⁰ K. Atkins, 'Autonomy and the subjective character of experience' (2000) *Journal of Applied Philosophy* 71-79.

¹²¹ C. Mackenzie, 'Relational autonomy, normative authority and perfectionism' (2008) 39 *Journal of Social Philosophy* 512-533.

¹²² Herring and Wall, n 14 above.

¹²³ Herring, n 9 above.

¹²⁴ Mackenzie, n 136 above.

¹²⁵ Feldman (1997) n 129 above.

¹²⁶ n 1 above.

¹²⁷ Herring, n 9 above.

perfectly capable of understanding a choice and expressing a view, provided that sufficient effort is put into enabling them to communicate using means other than words.¹²⁸

It is noteworthy that despite moves to outlaw discrimination over the course of the twentieth century, as recently as 1989, the views of one category of people in society – those suffering from impaired decision-making ability – were routinely treated as less worthy of respect than the views of others, in that they were customarily not listened to at all.¹²⁹ This is how we make decisions about animals, or about inanimate objects, but, as Jeremy Waldron explains, it should not be how we make decisions about people:

Applying a norm to a human individual is not like deciding what to do about a rabid animal or a dilapidated house. It involves paying attention to a point of view and respecting the personality of the entity one is dealing with. As such it embodies a crucial dignitarian idea – respecting the dignity of those to whom the norms are applied as beings capable of explaining themselves.¹³⁰

Taking seriously the views of the patient who lacks capacity has practical benefits aside from protection of the person's right to be treated with respect and dignity.¹³¹ It might, for example, have positive effects on her wellbeing and self-esteem, and on the quality of her relationship with healthcare professionals.¹³² Indeed, there is considerable evidence that providing opportunities for people with cognitive disabilities to exercise control and choice is associated with better outcomes for them.¹³³ As Oliver Lewis puts it, a 'finding of incompetence may end up being a self-fulfilling prophecy: we lose skills if we do not practice them. If other people take our decisions for us, we will become less talented at taking them ourselves'.¹³⁴

In making the point that 'for almost all people having some level of choice will, with suitable support, improve their lives', Jonathan Wolff describes especially well the sheer dreariness of life as a 'passive subject' of other people's decisions:

¹²⁸ J. Watson, 'Assumptions of Decision-Making Capacity: The Role Supporter Attitudes Play in the Realisation of Article 12 for People with Severe or Profound Intellectual Disability' (2016) 5 *Laws* 6.

¹²⁹ P. Weller, 'Reconsidering legal capacity: radical critiques, governmentality and dividing practice' (2014) 23 *Griffith Law Review* 498-518. Although outside the scope of this article, Dunn et al have pointed out that in cases in which the inherent jurisdiction has been used to protect vulnerable adults, it is striking that the voice of the vulnerable adult herself has sometimes been missing, see further Dunn et al, n 16 above.

¹³⁰ Waldron n 133 above.

¹³¹ Donnelly n 122 above.

¹³² *ibid*; Herring, n 9 above.

¹³³ A.E. Harchik, J.A. Sherman, J.B. Sheldon, and D.J. Bannerman, 'Choice and control new opportunities for people with developmental disabilities' (1993) 5 *Annals of Clinical Psychiatry* 151-161. See also H.I. Cannella, M.F. O'Reilly, and G.E. Lancioni, 'Choice and preference assessment research with people with severe to profound developmental disabilities: A review of the literature' (2005) 26 *Research in Developmental Disabilities* 1-15.

¹³⁴ O. Lewis, 'Advancing legal capacity jurisprudence' (2011) 6 *European Human Rights Law Review* 700-714.

Probably many ordinary citizens have given very little thought to what happens at a day centre, unless a story of abuse makes the newspapers. But the broader concern is not the possibility of abuse, but the mundane, dreary routine of it all. Although, no doubt there are many exceptions and examples of good practice, the danger is that such arrangements turn a person into a passive subject: a consumer rather than a producer; a recipient rather than a provider; someone who needs to be kept occupied or entertained, but has little to contribute to others except as an employment opportunity or for ‘doing good’. Individual life becomes an epiphenomenon of other people’s decisions.¹³⁵

Of course, if Article 8 simply requires that the patient’s views are heard, and does not demand any particular weight to be given to them, this might amount to mere tokenism. If Scott Baker J in his first instance judgment in *Re F (Mental Patient: Sterilisation)* had mentioned F’s reaction to an attempt to explain to her, using simple visual signs, what was proposed to be done, before making the decision that she should be sterilised because this was compatible with the *Bolam* test, would that have been sufficient? To listen to someone, and to treat their response with appropriate respect, in practice requires more than putting in place mechanisms to ensure that their views are sought. Treating what someone says with respect suggests that we should instead consider whether, in all the circumstances of the case, her wishes should be followed. This is particularly the case for refusals of unwanted medical treatment. Unlike requests for a particular treatment, which might be refused on resource grounds, or because the procedure is not clinically appropriate,¹³⁶ if a patient does not want something to be done to her body, there may be good reasons to respect that refusal, even if she lacks the mental capacity to take the decision for herself.

Article 12(4) of the UN Convention on the Rights of Persons with Disabilities (CRPD) requires that ‘measures relating to the exercise of legal capacity respect the rights, will and preferences of the person’. The Oxford English Dictionary’s definition of ‘respect’ is to ‘treat or regard with deference, esteem, or honour’, which implies more than simply taking P’s views into account. As Martin et al explain: ‘whatever “respect” means in this context, it must be something stronger than “consider,” even though it is less than “be absolutely bound by.”’¹³⁷ It would therefore appear that the Mental Capacity Act’s section 4 best interests checklist, which gives no particular priority to P’s ‘will and preferences’, and treats them as simply one relevant factor among many, is not compliant with Article 12(4) of the UN CRPD.

¹³⁵ J. Wolff, ‘Cognitive disability in a society of equals’, in E.F. Kittay and L. Carlson (eds), *Cognitive Disability and Its Challenge to Moral Philosophy* (Wiley-Blackwell: Oxford, 2010) 147-159.

¹³⁶ See, for example, the judgment of the Court of Appeal in *Burke* n 86 above, at [31]: ‘The proposition that the patient has a paramount right to refuse treatment is amply demonstrated by the authorities ... The corollary does not, however, follow, at least as a general proposition. Autonomy and the right of self-determination do not entitle the patient to insist on receiving a particular medical treatment regardless of the nature of the treatment.’

¹³⁷ Martin et al, n 4 above.

In what follows, I will suggest that it is possible to sketch out two circumstances in which there could be a presumption in favour of respecting an incapacitated patient's wish to refuse unwanted medical treatment. First, if respecting her refusal would not be likely to result in any significant harm to her, overruling her wishes would not serve an important medical purpose. The psychological and emotional harm, and the erosion of trust, that might be likely to result from imposing treatment upon her against her wishes would not be outweighed by significant health benefits. When the harms of treating and not treating her are weighed in the balance, it would be reasonable to come down in favour of respecting her desire not to receive the treatment in question.

Secondly, if respecting the person's wishes might result in significant harm to her, but those wishes nevertheless reflect her deeply and profoundly held values (rather than resulting from a phobia or delusion, for example), then Article 8 could require us to refrain from treating her against her wishes, despite this risk of harm.¹³⁸ Once again, the psychological harm that is done to someone by imposing treatment upon her, where to do so goes against beliefs that are profoundly important to her, should be put in the balance with the physical harm that might be caused if she does not receive the treatment in question. As Jonathan Herring has explained in the context of a discussion about whether the 'out of character' preferences of the 'just competent' should be respected:

A key issue then, where a person is wishing to engage in an act which will cause them harm, is to consider whether the act is an exercise of autonomy in the richest sense. That is whether it reflects beliefs that are central to him or herself and are an expression of identity. Where it is, it deserves respect; where it is not then it counts for less.¹³⁹

Of course, there will always be a small number of patients who have never been able to communicate, or who have never had any discernible wishes and values. In some cases, substitute rather than supported decision-making is therefore inevitable. But a scheme for according varying weight to the treatment refusals of patients who lack capacity better reflects the reality that people who lack capacity are not a homogenous group, and that a simple finding of incapacity does not necessarily justify overruling their wishes.

6. Giving weight to P's wishes

(a) Primacy unless significant harm

¹³⁸ Herring n 9 above.

¹³⁹ *ibid.*

The suggestion that P's wishes should have some level of primacy when determining what medical treatment is in her best interests is not new.¹⁴⁰ It appeared in the Law Commission's consultation paper on *Mental Capacity and Deprivation of Liberty*,¹⁴¹ and in their final recommendations and draft Bill.¹⁴² But to say that P's wishes should have priority, or 'be given particular weight',¹⁴³ does not set out in what circumstances it might be acceptable to give medical treatment to P against her wishes. Nor does it distinguish between refusals of unwanted treatment and positive requests for treatment, thus suggesting that a patient's wish not to undergo an invasive procedure need not be given any more weight than a patient's desire to receive a particular treatment.¹⁴⁴

In deciding whether to treat a patient against her wishes, those wishes are one factor, and the judgment of the treating clinician as to what treatment is in her best interests, is another. In such a scenario, following the patient's wishes might be likely to lead to harm, given that this is not the course of treatment that her clinician believes will lead to the best health outcome, while at the same time, there will be psychological or emotional harm to P from treating her against her wishes, which might be invasive and demeaning and, in some cases, positively traumatic.¹⁴⁵ Essentially, it is necessary to balance those two harms, in order to determine whether the harm from not receiving beneficial medical care is outweighed, or not, by the harm of having one's wish not to receive treatment overruled.

This balancing exercise could also be expressed more positively, in terms of weighing the benefits of enabling P to make a decision for herself, against the health benefits likely to flow from following medical advice. Being able to exercise some control over the risks to which she is exposed might benefit the person who lacks capacity, through what has been described as the 'dignity of risk'.¹⁴⁶ Peter Jackson J in *Wye Valley NHS Trust v B* explained this as follows:

It is, I think, important to ensure that people with a disability are not – by the very fact of their disability – deprived of the range of reasonable outcomes that are available to others. For people with disabilities, the removal of such freedom of action as they have to control their own lives may be experienced as an even greater affront that it would be to others who are more fortunate.¹⁴⁷

¹⁴⁰ Martin et al, n 4 above.

¹⁴¹ *Mental Capacity and Deprivation of Liberty: A Consultation Paper* Law Com no 222 (2015), para 12.45

¹⁴² *Mental Capacity and Deprivation of Liberty*, Law Com no 372 (2017).

¹⁴³ *ibid* para 14.17.

¹⁴⁴ cf *Burke* n 86 above.

¹⁴⁵ As Herring has pointed out, forced treatment might also be traumatic for staff and patients. See further, Herring n 9 above.

¹⁴⁶ S.M. Callaghan and C. Ryan, 'Is There a Future for Involuntary Treatment in Rights-based Mental Health Law?' (2014) 21 *Psychiatry, Psychology and Law* 747-766.

¹⁴⁷ n 67 above at [12].

Where the risk to P's health from not receiving the treatment she wishes to refuse is trivial, it is likely that the psychological harm from forcing treatment upon her will trump the harm from not receiving the recommended treatment. If the damage to P's health might be likely to be significant, the balancing act will be more difficult (as explained below), but the harm from going against P's wishes will continue to be real and significant. In *Surrey and Sussex Healthcare NHS Trust v AB*,¹⁴⁸ for example, a case in which Keehan J decided that it would be in the best interests of a woman who would be likely to die within the next 10 days if her leg was not amputated for the operation to go ahead, Keehan J nevertheless admitted that 'the impact of the proposed surgery on her mental health is unknown but, at least, in the first instance, is likely to be deleterious'.¹⁴⁹

For this presumption to be applied in practice, it will obviously be necessary to distinguish between a risk of trivial or significant harm. An example might be a failure to stitch a surface wound, which might mean that it does not heal as quickly, and that it leaves a more prominent scar. Although having the wound stitched might be in P's clinical best interests, the trauma of have stitches put in against one's wishes is likely to outweigh the harms of slightly slower healing and more visible scarring. Of course, distinguishing between trivial and significant harm will not always be straightforward, but in other contexts, the courts are accustomed to determining whether a risk of harm meets a threshold level of seriousness, such that state intervention becomes justifiable. In child protection proceedings, for example, a risk of non-significant harm to a child does not justify that child being taken into care. Rather, for the statutory threshold criteria to be met, the courts have established that the risk of harm to which the child is exposed must be 'considerable, noteworthy or important'.¹⁵⁰

Most commonly, the risk of harm from not undergoing the recommended procedure will be a risk of physical harm, to be put in the balance with the psychological or emotional harm that might result from treating her against her wishes. If the patient objects to treatment for her mental disorder, she might be likely to suffer harm to her mental health, in addition to (or instead of) harm to her physical wellbeing. Although such refusals are likely to raise difficult issues in practice,¹⁵¹ in principle, the same balancing act should apply, and if the risk of harm to a person's mental health through allowing her to refuse treatment would be trivial, it would be unlikely to outweigh the trauma that might be caused by forcing her treatment upon her.

¹⁴⁸ [2015] EWCOP 50.

¹⁴⁹ *ibid* at [59].

¹⁵⁰ *Re B (A Child)* [2013] UKSC 33

¹⁵¹ I return to the example of anorexia briefly below. If the patient had been sectioned, a refusal of treatment for her mental disorder might also be subject to sections 57-63 of the Mental Health Act 1983. For criticism of these provisions, see, for example, G. Richardson, 'Autonomy, Guardianship and Mental Disorder: One Problem, Two Solutions' (2002) 65 *Modern Law Review* 702-23.

Qualifying the primacy given to P's wish to refuse treatment by taking into account any risk of significant harm is a way of capturing the importance of not abandoning patients who lack capacity to their autonomy. I come back to this point below in the context of delusions and phobias, but as Michael Dunn and Charles Foster have explained, a narrow version of autonomy as a right to be left alone or 'free to fend for oneself' might mean that we fail to care properly for adults who cannot look after themselves: 'If one aims to deliver only the minimum level of support, one is teetering always on the brink of neglect'.¹⁵² The key question, as set out by Michael Bach and Lana Kerzner in their recommendations to the Ontario Law Commission is 'how the law can balance the right to autonomy while safeguarding people who may be vulnerable to abuse and neglect'.¹⁵³ Historically, the law has tended to 'protect' adults who lack capacity by adopting an 'overly-paternalistic approach which has undermined individual autonomy'.¹⁵⁴ A presumption in favour of following P's wishes reverses the traditional presumption in favour of paternalism, and instead requires there to be specific justification for a failure to respect P's wishes.

(b) Primacy even if significant harm, if the decision reflects P's deeply held values

Once it has been established that there is a risk of significant harm to P from following her wishes, the next stage might be for the decision-maker to ask herself whether the strength and depth of P's wishes are such that the risk of harm from treating her against her wishes might nevertheless outweigh the significant harm she is likely to suffer if she does not receive the medical treatment to which she objects (or has objected in the past, if she can no longer express a view). This will necessitate exploration of the importance to P of her wishes or values in relation to this treatment decision. So far, I have used terms like the patient's 'values', 'wishes', 'preferences' and 'beliefs' as if they are interchangeable, when of course they are not. Indeed, a patient's values, wishes and beliefs will sometimes be in tension with each other. A patient might 'prefer' not to receive a pain-killing injection, while also 'wishing' to be pain-free. Or a patient with a breech pregnancy might have a 'belief' in natural childbirth, at the same time as a 'desire' that her child is born alive. Untangling what matters most to the patient, and identifying what might be said to be her core values and beliefs, will not always be straightforward.

Nevertheless, it is clear that when a patient's wish reflects the way in which she has chosen to live her life, this should count for more than an out-of-character or fluctuating whim. In recent cases,

¹⁵² M. Dunn and C. Foster, 'Autonomy and Welfare as *amici curiae*' (2010) 18 *Medical Law Review* 86-95.

¹⁵³ M. Bach and L. Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (Law Commission of Ontario, October 2010).

¹⁵⁴ *ibid.*

there is evidence of judges in the Court of Protection seeking to understand what has mattered most to the patient over the course of her life – whether that be ‘respectability, security and a good face to the world’;¹⁵⁵ ‘fierce independence’;¹⁵⁶ ‘privacy, personal autonomy and dignity’;¹⁵⁷ or a religious belief that ‘someone else should not play an assisting role in shortening life merely because of the subjective quality of that life’.¹⁵⁸ As Johnston et al explain, ‘the way a person has lived their life – what we could describe as their narrative up to and beyond the point of incapacity - seems increasingly to have legal relevance in the determination of current best interests’.¹⁵⁹ And Johnston et al further point out that tools are being developed which enable busy healthcare professionals to access this sort of ‘narrative’ information about the values and beliefs that have mattered most to their patients.¹⁶⁰

It will also often be necessary to distinguish between wishes which reflect a person’s core values, and wishes which instead are the result of delusions, phobias or addictions. Not ‘all statements about “what I want”’ are, in fact, ‘meaningful acts of “will”’.¹⁶¹ To respect the wishes of someone suffering from psychosis or delirium is not to treat her with dignity, but might instead amount to abandoning her when she needs help and support. A patient who is refusing a blood transfusion as a result of her needle phobia needs support in order to enable her to receive treatment which she would want to receive if she could see beyond her overwhelming fear of injections. In a case like this, properly ‘supported’ decision-making might amount to treatment without consent: the risk of harm is significant, and the patient’s terror of needles does not reflect her deeply held values.¹⁶²

In *Cambridge University Hospitals NHS Foundation Trust v BF*,¹⁶³ Macdonald J had to determine whether a total abdominal hysterectomy was in the best interests of a woman suffering from severe paranoid schizophrenia who had been diagnosed with Stage IIIB ovarian cancer. Her expressed wishes

¹⁵⁵ *M v N* [2015] EWCOP 76 at [58].

¹⁵⁶ *Wye Valley* n 67 above at [43].

¹⁵⁷ *Sheffield Teaching Hospitals v TH* [2014] EWCOP 4 at [53]. See also *United Lincolnshire Hospitals NHS Trust v N* [2014] EWCOP 16 at [29].

¹⁵⁸ *St George’s NHS Foundation Trust v P* [2015] EWCOP 42 at [38].

¹⁵⁹ C. Johnston, N. Banner, and A. Fenwick, ‘Patient narrative: an “on-switch” for evaluating best interests’ (2016) 38 *Journal of Social Welfare and Family Law* 249-262.

¹⁶⁰ See, for example, the ‘life story toolkit’ produced by Dementia UK available at <https://www.dementiauk.org/for-healthcare-professionals/free-resources/life-story-work/> (last accessed 4 August 2017). See also Irene J Higginson et al, ‘Development and evaluation of the feasibility and effects on staff, patients, and families of a new tool, the Psychosocial Assessment and Communication Evaluation (PACE), to improve communication and palliative care in intensive care and during clinical uncertainty’ (2013) 11 *BMC Medicine* 213.

¹⁶¹ Callaghan and Ryan, n 161 above.

¹⁶² The law’s solution to cases of needle phobia, like *Re MB* n 10 above, has been to find that the patient lacks decision-specific capacity in relation to the injection, and hence it can be given in her best interests, in order that she might be provided with the operation to which she has competently consented. Jonathan Herring has argued that this may misrepresent the reality of such cases, which are that, in the case of MB, she simply had contradictory wishes – to undergo a caesarean section and deliver a live baby, on the one hand, and to refuse an injection, on the other – and that one of these preferences was patently more important to her than the other. See further Herring, n 8 above, 56.

¹⁶³ [2016] EWCOP 26.

were contradictory: when she had capacity, she had agreed to the treatment and signed a consent form, but later she had said that she did not want the operation to go ahead, on the grounds that ‘bad voices’ and ‘bad machines’ were controlling her mind. Without the operation, she might be likely to die within six months. The risk of harm was significant, and the grounds for her refusal were the result of ‘intrusive auditory hallucinations telling her not to have the surgery’.¹⁶⁴ MacDonald J was therefore convinced that BF would be likely to ‘prioritise potentially life-saving treatment and the chance of continued life over the opportunity to bear children in the circumstances where, left untreated, her ovarian cancer will likely result in her death’.¹⁶⁵

Anorexia nervosa presents a particular challenge here.¹⁶⁶ On the one hand, it is hard not to be sympathetic to the view expressed by E’s parents in *A Local Authority v E*:¹⁶⁷

It seems strange to us that the only people who don't seem to have the right to die when there is no further appropriate treatment available are those with an eating disorder. This is based on the assumption that they can never have capacity around any issues connected to food. There is a logic to this, but not from the perspective of the sufferer who is not extended the same rights as any other person.¹⁶⁸

On the other hand, it is clear that people with anorexia often feel controlled by their condition,¹⁶⁹ and the ‘desire’ not to consume calories is not necessarily a reflection of deeply held values, but may instead be a symptom of what Charland et al describe as a destructive and all-consuming ‘passion’:

It is not clear that a person driven by a passion is acting autonomously. ...To help the person to be free from the grip of the passion and attain a greater degree of autonomy over her life, it may be necessary to impose upon her a routine that has a chance of breaking down the self-destructive patterns of behavior that is both part of, and helps to maintain, the passion that is anorexia nervosa.¹⁷⁰

As Tan et al explain, it is common for patients with anorexia to experience considerable ambivalence about treatment:

First, there may be advantages to having anorexia nervosa, which the patient may not wish to give up.

Second, the patient may feel that changing behaviour is not a choice she can make, even if she wants to.

¹⁶⁴ *ibid* at [53].

¹⁶⁵ At [65].

¹⁶⁶ See further B. Clough, ‘Anorexia, Capacity, and Best Interests: Developments in the Court of Protection Since the Mental Capacity Act 2005’ (2016) 24 *Medical Law Review* 434-445; C.J. Ryan and S. Callaghan, ‘Treatment refusal in anorexia nervosa: the hardest of cases’ (2014) 11 *Journal of Bioethical Inquiry* 143-45.

¹⁶⁷ n 62 above.

¹⁶⁸ *ibid* at [52].

¹⁶⁹ J. Craigie, T. Hope, J. Tan, A. Stewart, and J. McMillan ‘Agency, ambivalence and authenticity: the many ways in which anorexia nervosa can affect autonomy’ (2013) 9 *International Journal of Law in Context* 20-36.

¹⁷⁰ L.C. Charland, T. Hope, A. Stewart and J. Tan, ‘Anorexia nervosa as a passion’ (2013) 20 *Philosophy, Psychiatry, & Psychology* 353-365.

Third, the patient may wish to be coerced before she can comply with treatment. Fourth, the patient may feel simultaneous wishes to have and not to have treatment.¹⁷¹

Of course, that does not mean that treatment without consent is always justifiable in patients with anorexia,¹⁷² rather, careful and sensitive assessment of the depth and strength of each individual's 'will and preferences' will be necessary.¹⁷³

Also challenging are scenarios in which the patient's current wishes appear to contradict the values and beliefs that mattered to her when she had capacity. If the patient had executed a valid and applicable advance decision (AD) in relation to the treatment in question, that is binding upon the medical team, unless they have reasonable grounds for believing that she has subsequently done anything 'clearly inconsistent' with the advance decision.¹⁷⁴ But in the absence of a binding AD, a judgment will have to be made as to whether the patient's past wishes were sufficiently deeply held and profoundly important that they justify overriding her present preferences. There is insufficient space here to explore the broader philosophical question of whether a patient's 'precedent autonomy' should trump her present wishes, and therefore be binding upon her after she loses capacity.¹⁷⁵ In practice, if there are reasonable grounds for doubt about what matters to the patient, then just as when there is doubt about the validity or applicability of an advance decision, protecting her from harm might reasonably take priority.¹⁷⁶

(c) What if the patient cannot express a view?

If the patient cannot express a view about the proposed treatment, and did not execute an advance decision before she lost capacity, the decision-maker should be under a duty to try to ascertain her previously expressed values and beliefs, in order to work out what choice she would be likely to have made if she had capacity. In these circumstances, it may make sense to adopt the UN Committee on the Rights of Persons with Disabilities' formulation that 'where it is not practicable to determine the will and preferences of an individual, the "best interpretation of will and preferences" must replace the "best

¹⁷¹ J. Tan, T. Hope, and A. Stewart, 'Competence to refuse treatment in anorexia nervosa' (2003) 26 *International Journal of Law and Psychiatry* 697-707.

¹⁷² See, for example, *Betsi Cadwaladr* n 75 above.

¹⁷³ Clough, n 181 above.

¹⁷⁴ Mental Capacity Act 2005, section 25(2)(c).

¹⁷⁵ See further R. Dworkin, 'Autonomy and the demented self' (1986) *The Milbank Quarterly* 4-16; A. Buchanan, 'Advance directives and the personal identity problem' (1988) *Philosophy and Public Affairs* 131-54; I. de Beaufort 'The view from before' (2007) 7 *American Journal of Bioethics* 57-8.

¹⁷⁶ Mental Capacity Act 2005 Code of Practice, para 9.58.

interests” determinations’.¹⁷⁷ The decision-maker, and in the Court of Protection the judge, will have to evaluate such evidence as there is of her previous wishes. This is not always straightforward, since it will often involve relying upon the testimony of family members, who might find it challenging to separate out what P would have wanted from what they want for P.¹⁷⁸ It is also possible that P might have expressed apparently contradictory wishes and beliefs in the past, for example, a belief in the sanctity of human life and a preference not to be kept alive in a vegetative state.

Once P’s wishes and beliefs have been identified, they will have to be put in the balance with other considerations. If the risk of harm from not receiving the recommended treatment is significant, then P’s previously expressed wish not to receive a particular treatment should be permitted to trump the need to protect her from physical harm, but only if it has been established that her refusal was grounded in beliefs that mattered deeply to her.

(d) What if the patient has never been able to express a view?

In the tiny number of cases in which there is no view from P to take into account, because she has never had the capacity to hold or express any beliefs or preferences, decisions about her medical treatment have to be taken by others. In cases of ‘factual incapability to act or decide’,¹⁷⁹ where what Kim Atkins has called ‘the subjective character of experience’¹⁸⁰ is either absent or completely undetectable, it is better to admit the inevitability of substitute decision-making than to pretend that the decision-maker can engage realistically in ‘supported’ decision-making, or give a ‘best interpretation of P’s will and preferences’. Where decisions have to be taken without any reference to the views, values or preferences of P, substitute decision-making is justifiable because P is unable to contribute anything to the decision and therefore needs others to take decisions on her behalf, based upon their assessment of P’s needs and interests. This could continue to be framed as the Mental Capacity Act’s ‘best interests’ test, or as the Scottish test that any intervention ‘will benefit the adult and that such benefit cannot reasonably be

¹⁷⁷ UN Committee on the Rights of Persons with Disabilities, *General comment No. 1 (2014) Article 12: Equal recognition before the law* Eleventh session 31 March–11 April 2014, para 21.

¹⁷⁸ See, for example, *Abertawe Bro Morgannwg University Local Health Board v RY* [2017] EWCOP 2.

¹⁷⁹ A. Ruck Keene and A.D. Ward, ‘With and Without “Best Interests”: the Mental Capacity Act 2005, the Adults With Incapacity (Scotland) Act 2000 and constructing decisions’ (2016) 22 *International Journal of Mental Health and Capacity Law* 17–37.

¹⁸⁰ Atkins, n 135 above.

achieved without the intervention'.¹⁸¹ In either case, this is not deciding what P would want if she had capacity, because what P would want is not just difficult to determine, it is impossible.

It is in relation to this very small number of patients for whom no view, past or present, can be identified that the UN Committee on the Rights of Persons with Disabilities' *General Comment* appears to some commentators to part company with reality.¹⁸² According to the *General Comment*, it is never permissible for anyone other than the person concerned to appoint a substitute decision-maker. Nor is it acceptable ever to invoke the person's best interests when deciding how to treat them; according to the *General Comment*: 'The "best interests" principle is not a safeguard which complies with article 12 in relation to adults.

But if the person has never had any discernible will or preferences, the 'legal fiction' of coming to the 'best interpretation' of her will and preferences will be masking the fact that the decision can be taken only in the light of what others believe to be in P's interests.¹⁸³ As Mary Donnelly has argued, admitting that this is necessarily substituted, rather than supported decision-making facilitates 'rigorous oversight' of the decision-maker's paternalistic judgment, rather than deflecting scrutiny through the 'subterfuge' that the decision simply reflects P's 'will and preferences'.¹⁸⁴

It is worth noting that the Committee's *General Comment* is not binding on the UK, and that its interpretation of the Convention may be open to challenge. For example, the *General Comment* states unambiguously that 'States parties' obligation to replace substitute decision-making regimes by supported decision-making requires ... the abolition of substitute decision-making regimes'. The Convention itself does not state that substitute decision-making must be abolished, nor does the Convention explicitly prohibit 'best interests' decision-making.¹⁸⁵ If P has never had any will and preferences, invoking non-existent 'will and preferences' in order to come to what is, in fact, a 'best interests' decision involves unhelpful and potentially distracting sleight of hand.

7. Presumptions vs judicial discretion

¹⁸¹ Adults with Incapacity (Scotland) Act 2000, section 1(2). It is, however, worth noting that Ruck Keene and Ward (above n 194) found that, in practice, Scottish sheriffs have chosen increasingly to base their decisions upon what they consider to be in the adult's best interests.

¹⁸² See, for example, M. Parker, 'Getting the Balance Right: Conceptual Considerations Concerning Legal Capacity and Supported Decision-Making' (2016) 13 *Journal of Bioethical Inquiry* 381-393.

¹⁸³ Coggon, n 9 above.

¹⁸⁴ M. Donnelly, 'Best Interests in the Mental Capacity Act: Time to say Goodbye?' (2016) 24 *Medical Law Review* 318-332. See also L. Harmon, 'Falling off the vine: Legal fictions and the doctrine of substituted judgment' (1990) 100 *Yale Law Journal* 1-71.

¹⁸⁵ Martin et al, n 4 above.

I am not suggesting that the presumptions set out above represent a novel approach. On the contrary, it could be argued that they simply formalise what appears to be current best practice in the Court of Protection. There is certainly no doubt that judges sitting in the Court of Protection are now going to considerable lengths to determine what P would have wanted, and to make sure that the decision reflects what P would have decided for herself. Charles J's 2016 practice guidance on *Facilitating the participation of P and vulnerable persons in CoP proceedings*,¹⁸⁶ is clear that 'In order for P to be placed at the centre of the proceedings, P's wishes and feelings on the issues to be determined by the Court are of vital importance in Court of Protection proceedings'.¹⁸⁷ And in *Briggs v Briggs*,¹⁸⁸ Charles J concluded his judgment by saying that he was 'sure that if Mr Briggs had been sitting in my chair and heard all the evidence and argument he would, in exercise of his right of self-determination, not have consented to further CANH treatment'.¹⁸⁹

In *Sheffield Teaching Hospitals NHS Foundation Trust v TH*,¹⁹⁰ in order to build the fullest possible account of what TH would have wanted, Hayden J heard evidence from those closest to him, and from the healthcare professionals involved in his care. TH was now in a minimally conscious state, able only to make noises 'peppered with occasional expletives'.¹⁹¹ The court had nevertheless heard a sufficiently 'holistic account of [TH's] character, life, talents and priorities',¹⁹² that Hayden J was:

left in no doubt at all TH would wish to determine what remains of his life in his own way not least because that is the strategy he has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-wife and his mate's Spud and end his days quietly there and with dignity as he sees it'.¹⁹³

But while it would be possible to describe this decision as one in which Hayden J gave priority to TH's wish to have no further treatment because that reflected his deeply held values, the judiciary has tended to resist further specification of the best interests test, on the grounds that these cases are fact-specific,¹⁹⁴ and 'infinitely variable'.¹⁹⁵ For example, in *M v N*,¹⁹⁶ in setting out the respect to be afforded to P's wishes under the Mental Capacity Act, Hayden J explained that:

¹⁸⁶ Charles, n 125 above.

¹⁸⁷ *ibid*, para 9.

¹⁸⁸ n 69 above.

¹⁸⁹ *ibid* at [129].

¹⁹⁰ n 172 above.

¹⁹¹ *ibid* at [52].

¹⁹² *ibid* at [53].

¹⁹³ *ibid* at [53].

¹⁹⁴ See, for example, *Re M (Statutory Will)* n 58 above at [35].

¹⁹⁵ *per* Hedley J in *Portsmouth NHS Trust v Wyatt* [2004] EWHC 2247 (Fam) at [23].

¹⁹⁶ [2015] EWCOP 76.

Respecting individual autonomy does not always require P's wishes to be afforded predominant weight. Sometimes it will be right to do so, sometimes it will not. The factors that fall to be considered in this intensely complex process are infinitely variable e.g. the nature of the contemplated treatment, how intrusive such treatment might be and crucially what the outcome of that treatment maybe for the individual patient. Into that complex matrix the appropriate weight to be given to P's wishes will vary.¹⁹⁷

Similarly, in *Wye Valley NHS Trust v B*,¹⁹⁸ Peter Jackson said that: 'there is no theoretical limit to the weight or lack of weight that should be given to the person's wishes and feelings, beliefs and values. In some cases, the conclusion will be that little weight or no weight can be given; in others, very significant weight will be due'.¹⁹⁹

The weight given to P's wishes will inevitably vary, but at the same time, it might be helpful, especially for clinicians, patients and relatives, if an attempt was made to set out the circumstances in which P's wishes normally might be expected to be either disregarded or followed. Indeed, in *M v N*,²⁰⁰ Hayden J appeared to suggest that there should be just such a presumption, where the wishes of an incapacitated adult are 'important', and communicated with 'cogency and authenticity':

the presumption of life, predicated on what is often referred to as the 'sanctity of life' or the 'intrinsic value of life', can be rebutted (pursuant to statute) on the basis of a competent adult's cogently expressed wish. It follows, to my mind, by parity of analysis, that the importance of the wishes and feelings of an incapacitated adult, communicated to the court via family or friends but with similar cogency and authenticity, are to be afforded no less significance than those of the capacitous.²⁰¹

In this case, with the help of her family, Hayden J had painted a vivid picture of Mrs N's personality and priorities, through which it had become evident that '[f]ew ... were less well placed to withstand the ravages and vicissitudes of this degenerative disease than Mrs N'.²⁰² Hayden J was therefore:

left with little doubt that Mrs. N would have been appalled to contemplate the early pain, increasing dependency and remorseless degeneration that has now characterised her life for so long. I have no difficulty in accepting the family's view that she would not wish to continue as she is.²⁰³

The recognition that these cases are fact-specific and that the decision that ANH should be withdrawn from Mrs N does not have any precedent value when deciding whether to withdraw ANH from a future Mrs O, P or Q, need not bar the construction of a 'roadmap' in order to guide future decision-making.

¹⁹⁷ *ibid* at [28].

¹⁹⁸ n 67 above.

¹⁹⁹ *ibid* at [10].

²⁰⁰ n 211 above.

²⁰¹ *ibid* at [32].

²⁰² *ibid* at [57].

²⁰³ *ibid* at [60].

Indeed, Rob Heywood and Alexandra Mullock have suggested that one could detect a more general trend away from objective substitute decision-making in *M v N*, and in particular from Hayden J's decision to 'justify his decision *solely* by reference to what he thought the patient would have wanted to happen' (emphasis in original). According to Heywood and Mullock, *M v N* offers compelling evidence that 'the objective component to the best interests assessment may be withering on the vine'.²⁰⁴

But in the absence of any official presumptions about the weight to be given to P's wishes, radically different interpretations are clearly possible. In *Wye Valley v B*,²⁰⁵ *Sheffield Teaching Hospitals NHS Foundation Trust v TH*,²⁰⁶ and *M v N*,²⁰⁷ for example, the Official Solicitor appeared to be applying a definition of best interests which was at odds with that of the judge. In *Sheffield Teaching Hospitals NHS Foundation Trust v TH*, Hayden J recorded, with surprise, that 'the Official Solicitor's lawyers appear not to share my analysis of the cogency and strength of TH's wishes regarding his treatment'.²⁰⁸ Hayden J put this down to the fact that they had 'not absorbed the full force of Lady Hale's judgment in *Aintree* and the emphasis placed on a 'holistic' evaluation when assessing both "wishes and feelings" and "best interests"'.²⁰⁹ And in *M v N*, at the outset of the case, 'and until the conclusion of the family's evidence the Official Solicitor took the view that the strong presumption in favour of the benefit of the continuance of life had not been displaced'.²¹⁰

As we saw earlier, the House of Lords Select Committee heard evidence that the best interests test was poorly understood by clinicians,²¹¹ who, according to the British Institute of Learning Difficulties, too frequently interpreted it 'in a medical/paternalistic sense which is wholly at odds with that set out in the Act'.²¹² And respondents to the Law Commission's 2017 consultation on mental capacity confirmed that the 'concept of best interests was often interpreted in a medical and paternalistic sense':

²⁰⁴ R. Heywood and A. Mullock, 'The value of life in English law: revered but not sacred?' (2016) 36 *Legal Studies* 658–682.

²⁰⁵ n 67 above at [41].

²⁰⁶ n 172 above.

²⁰⁷ n 211 above.

²⁰⁸ *ibid* at [55].

²⁰⁹ *ibid* at [55].

²¹⁰ *ibid* at [62].

²¹¹ See also P. Willner et al, 'What do NHS staff learn from training on the Mental Capacity Act (2005)?' (2013) 18 *Legal and Criminological Psychology* 83–101.

²¹² The British Institute of Learning Disabilities, cited in House of Lords Select Committee on the Mental Capacity Act 2005, n 18 above, para 90. One of the Select Committee's witnesses went so far as to say that 'the term "best interests" is probably the most abused and misunderstood phrase in health and social care. It has too often been the vehicle for poor decision-making' (Dr Claud Regnard, para 90).

Family carers reported that best interests decisions by health and social care professionals were often made without reference to their loved one's wishes and feelings, and that professionals often "pick and choose" which factors on the check-list to prioritise to suit their own preferred outcomes.²¹³

If the best interests test continues to be misapplied by those who are most frequently responsible for taking medical decisions for adults who lack capacity,²¹⁴ giving some further structure to decision-making under the statute may lead to better decisions, and greater consistency.²¹⁵ The flexibility of the section 4 checklist has undoubtedly enabled the judiciary to apply it sensitively and empathetically, in order to produce patient-centred decisions about what medical treatment is in P's best interests. But with the advantages of flexibility come the potential disadvantages of inconsistency, such as the likelihood that different decision-makers will come to different decisions on the same facts.²¹⁶ If respect for the patient's wishes matters, it is unsatisfactory for too much to turn on who happens to be making the best interests assessment on any particular day.

In *A Local Authority v E*,²¹⁷ Peter Jackson J acknowledged that, when deciding whether force feeding was in E's best interests, 'any decision is a heavy one', at the same time as admitting that 'The balancing exercise is not mechanistic but intuitive and there are weighty factors on each side of the scales'.²¹⁸ Given the negative consequences for P of being treated against her wishes, it might be argued that a more structured approach to determining when P might reasonably expect to have her refusal of treatment respected may be preferable to an approach grounded in judicial intuition.²¹⁹

I am not advocating the removal of discretion and the replacement of the non-exhaustive best interests checklist with an inflexible formula. Instead, rebuttable presumptions leave open the possibility of cases for which they are a poor fit. The purpose of the presumptions described above is instead to shape best interests decision-making in order that respect for the patient's wish to refuse treatment is

²¹³ Law Commission, n 157 above, para 14.7.

²¹⁴ As Emma Cave has explained: 'The MCA's concessions to a relational approach focus on enablement and the relevance of the person's past and present views when making a decision in their best interests, but they are poorly implemented. The legislation is not currently living up to its promises to protect and promote even this limited conception of relational autonomy'. E. Cave, 'Determining Capacity to Make Medical Treatment Decisions: Problems Implementing the Mental Capacity Act 2005' (2015) 36 *Statute Law Review* 86-106.

²¹⁵ Better training may also be necessary, see further K. Hinsliff-Smith et al, 'What do we know about the application of the Mental Capacity Act (2005) in healthcare practice regarding decision-making for frail and older people? A systematic literature review' (2017) 25 *Health & social care in the community* 295-308.

²¹⁶ Taylor, n 23 above.

²¹⁷ n 62 above.

²¹⁸ *ibid* at [129].

²¹⁹ J. Coggon, 'Anorexia nervosa, best interests, and the patient's human right to "a wholesale overwhelming of her autonomy": *A Local Authority v. E*' [2012] EWHC 1639' (2014) 22 *Medical Law Review* 119-130.

not conditional upon the ‘all or nothing’ cliff edge of capacity.²²⁰ Where a patient has failed the capacity test, there may still be good reasons to give effect to her preference not to receive a particular treatment, if this would not cause her significant harm, or if that preference is a product of her core values and beliefs. This may now be best practice in the Court of Protection, but it is not self-evident that it embodies current practice among healthcare professionals, or even of the Official Solicitor.

I am conscious that judges, in particular, are likely to balk at the introduction of statutory presumptions into these inevitably fact-specific cases,²²¹ and that it might be more acceptable to include them in the Code of Practice, and perhaps to describe them instead simply as ‘starting points’. In both cases, however, specific and defensible justification for departing from the presumption or starting point should be required. Regardless of how it is formulated, busy and non-legally trained healthcare professionals are unlikely to consult the law reports regularly, and need clearer prospective guidance than the Act and its Code of Practice currently provides that an incapacitated patient’s refusal of medical treatment should be taken seriously, and should be overruled only if the risk to which she would thereby be exposed meets a threshold level of seriousness, *and* her refusal is not grounded in values or beliefs that are of profound importance to her.

7. Conclusion

In *Kings College Hospital NHS Foundation Trust v C*,²²² Macdonald J was faced with ‘a finely balanced case that sits close to the border that runs between an individual with capacity making an unwise decision and an individual lacking capacity to make the decision in question’.²²³ C was refusing to consent to dialysis, without which she would die. There was some evidence that C suffered from a personality disorder, but C’s daughter believed that her mother had:

reached a clear and reasoned decision by giving weight to the factors that are important to her (a risk of a life lived on dialysis that is unacceptable to her, a risk of long term disability that is unacceptable to her, exhaustion with treatment and her wish not to endure further weeks or months of the same, her wish not to continue to endure the symptoms and pain associated with treatment, the risk she will not be able to attain

²²⁰ M. Browning, C. Bigby, and J. Douglas, ‘Supported decision making: Understanding how its conceptual link to legal capacity is influencing the development of practice’ (2014) 1 *Research and Practice in Intellectual and Developmental Disabilities* 34-45.

²²¹ Although a subsection which covers a particular sort of decision, and a particular sort of value or belief, might seem peculiar, it is worth noting that section 4(5) refers to a particular sort of medical treatment, and whether a particular outcome is ‘desired’.

²²² [2015] EWCOP 80.

²²³ *ibid* at [64].

her former “sparkly” lifestyle, her desire not to get old and lose her appearance and her wish to attain her original goal of ending her life).²²⁴

In concluding, on balance, that C did have capacity, and hence was entitled to refuse to consent to dialysis, Macdonald J’s decision was at odds with ‘the considered opinions of two very experienced psychiatrists’.²²⁵ He explained this disagreement as being ‘in large part a product of this being a finely balanced case in which a number of reasonable interpretations of the information available are possible’.²²⁶

It could be argued that this case offers a good illustration of the artificial cliff edge created by the binary threshold test for capacity. If C had capacity, she could make the ‘foolish’ decision to refuse dialysis. If C lacked capacity, the decision would be taken for her, in her best interests. The presumptions set out above would mean that, in a case like that of C, less would turn on the ‘finely balanced’ question of whether C’s personality disorder had impaired her decision-making ability. Instead, because C’s wish to refuse treatment was clearly the product of values that mattered deeply to her, then despite the risk of significant harm, there might be a presumption that her refusal to undergo dialysis should be respected, even if she lacked capacity.

It might be argued that rigorous application of section 1 of the Mental Capacity Act 2005, including the presumption of capacity,²²⁷ and the principle that ‘a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success’,²²⁸ should mean that fewer people fail the MCA’s capacity test, and hence are able to take decisions, including unwise decisions,²²⁹ for themselves. But even if it is possible that more people might be able to make decisions for themselves if more resources were put into helping them to do so, if there continues to be a legal test for capacity based upon people’s ability to weigh information in the balance in order to arrive at a choice, there will continue to be people who fail the capacity test. Given evidence of inconsistent best interests decision-making, including failures to treat P’s wishes with appropriate respect, it seems sensible to consider giving decision-makers clearer guidance on how to resolve any tension between P’s beliefs and her doctor’s medical advice.

²²⁴ *ibid* at [69].

²²⁵ *ibid* at [94].

²²⁶ *ibid* at [94].

²²⁷ Section 1(2).

²²⁸ Section 1(3).

²²⁹ Section 1(4).

In its final report and draft Bill, the Law Commission has proposed that the legislation is amended to ensure that decision-makers must ‘ascertain’, rather than merely ‘consider’ P’s wishes,²³⁰ and that they ‘must give particular weight to any wishes or feelings ascertained’.²³¹ The draft Bill also places additional requirements on decision-makers ‘to explain their decisions not to follow wishes and feelings’.²³² Some respondents had recommended the introduction of a ‘rebuttable presumption that [P’s] wishes and feelings should be followed (with departure only occurring if there were “compelling reasons” or “serious adverse consequences”’).²³³ While the Law Commission was ‘attracted by the idea of a rebuttable presumption’, it concluded that this could not be achieved by a simple amendment to section 4, but would instead ‘require the amendment of section 1’, in order that P’s wishes could trump the section 1(5) principle that any act done for P must be done in her best interests.²³⁴ This option had not been consulted upon and, according to the Law Commission, ‘would be far beyond our remit’.²³⁵

The Law Commission’s proposals are undoubtedly a further positive step in the direction of treating P’s views as worthy of particular respect. It could, however, be argued that the more specific presumptions outlined above would be easier for patients, relatives and healthcare professionals to understand, and have significantly more teeth than a requirement simply to give P’s wishes ‘particular weight’. If the court is under a duty to ‘ascertain’ P’s views, this might be implemented most effectively through a presumption that P is heard from directly in any case involving her medical treatment.

Presumptions instruct decision-makers, and, crucially, reassure P, that falling on the ‘wrong’ side of the capacity cliff edge, now or in the future, will not convert P’s life into one over which she has no decision-making authority. Giving P’s wishes ‘particular weight’ does not tell decision-makers, and P herself, in advance, when she might reasonably expect to receive the same respect for her interest in exercising control over what is done to her body as those of us who are, for now, fortunate enough to fall on the other side of the capacity cliff edge.

²³⁰ Law Commission, n 157 above, para 14.16.

²³¹ *ibid*, para 14.17.

²³² *Ibid*, para 14.19.

²³³ Law Commission, n 157 above, para 14.8. See also A. Ruck Keene and C. Auckland, ‘More presumptions please? Wishes, Feelings and Best Interests Decision-making’ (2015) 5 Elder Law Journal 293-301.

²³⁴ *ibid*, para 14.14.

²³⁵ *ibid*.